

**State Advisory Council on Quality Care at the End of Life
Minutes from the May 20, 2013 Meeting**

Meeting time and place: May 20, 2013, 10:00 a.m, Department of Aging, 301 West Preston Street, Baltimore, Maryland.

Council members present: Ted Meyerson, Chair; Lya Karm; Hope Miller; Karen Kauffman; Paul Ballard (Attorney General's designee); Tricia Tomsko Nay (Department of Health and Mental Hygiene's designee); Donna Leister; Delegate Dan Morhaim; Michael Safra; George Failla (Department of Disabilities' designee); Steve Levenson; Gail Amalia Katz; Gail Mansell. On speakerphone: Gail Mansell; Catherine Stavely; Gail Amalia Katz; Karren Pope-Onwukwe; Michael McHale; Mary Lynn McPherson.

Others present: Alice Hedt on behalf of the Department of Aging; Pat Alt; Alan Eason. On speakerphone: Lawanda Edwards on behalf of Senator Roger Manno.

Chairman Ted Meyerson convened the meeting at 10:00 a.m.

Ted Meyerson showed the Council an educational video for consumers on advance directives and the Maryland Medical Orders for Life-Sustaining Treatment (MOLST) form he had prepared as a demonstration of what might be produced at low cost. He asked the Council for their comments and suggestions. Lya Karm suggested that the video be reviewed with the literacy level of the target audience in mind, adding that focus groups might help the Council ascertain whether the video's messages are clear. She also suggested separate headings for the discussions of advance directives and the MOLST form. Delegate Morhaim suggested it might be good for a minority speaker to be featured on the video and it might also be good to have someone famous as the speaker. Michael Safra suggested it would be good to explain how an advance directive is different than a MOLST form.

Alice Hedt suggested it would help if the video was edited into two parts. She believed examples are needed to make the issues real for the audience. She could envision it being used to educate families in nursing homes and that it would be helpful for them to see videos on these issues. Steve Levenson stated it is important to have the conversation about these issues and that the MOLST form is simply the end point of the conversation. He noted that the MOLST form is not an advance directive but serves many of the purposes of an advance directive. Ted Meyerson noted that a MOLST form serves a different function than an advance directive in that the MOLST form contains medical orders.

Delegate Morhaim stated that the problem is society is resistant to talking about the subject of dying and noted that it takes time to change cultural expectations, citing as an example the public education campaign regarding the dangers of cigarette smoking. He suggested that more could be done with National Advance Directive Day to educate the public. Karren Pope-Onwukwe stated that the Maryland Elder Law Section does an Advance Directive Day combined with Law Day where they prepare advance directives and counsel people regarding them. She noted that even an 18-year old should have an advance directive prepared. Ted Meyerson told the Council that he would revise the video's text and distribute it to the Council.

Ted Meyerson then asked the Council to consider what projects should next be undertaken by the Council. Karen Kauffman suggested that there could be more education given to the prison population regarding end of life care issues. Steve Levenson then described what the Council has done in the past and gave the Council a chart he had prepared summarizing the Council's activities from 2003 through 2013. He stated that some projects had resulted in legislation, other projects were taken over by other organizations, and some ideas just remained subjects of discussion without resulting in projects. He suggested that the Council may wish to consider talking with newer agencies regarding ideas that had not previously resulted in projects.

Delegate Morhaim suggested that the Maryland Medicaid Commission might look at the issue of end of life care. He also suggested that the Department of Health and Mental Hygiene's Minorities Health Disparities Commission might be interested in examining the issues of end of life care. Michael Safra stated there is a lack of education of average people regarding end of life care issues. Tricia Nay stated that the Maryland Health Care Commission has a workgroup on expanding awareness of hospice care in underserved communities. Michael Safra said the Council could obtain the research done by that workgroup and volunteered to represent the Maryland Health Care Commission workgroup on behalf of the Council

Ted Meyerson said that training for end of life care directed at clinical staff could be put on YouTube and that information could be made available to African-American churches. Karren Pope-Onwukwe stated that there needs to be concerted effort to educate the public and that from her experience she does not believe there is any resistance to such education. She noted that people should be told of their options for care at the end of life such as hospice regardless of their economic circumstances.

Tricia Nay noted that the Office of Health Care Quality gives out grant money from its funds collected from civil money penalties imposed upon nursing homes and assisted living programs and suggested the Council might endorse projects that seek such grants to improve the quality of care in these programs. Lynn McPherson suggested that an online training program regarding improvement of the care of patients with advanced illness could be developed with the grant money. Lynn McPherson, Pat Alt, Karen Kauffman, and Lawanda Edwards all agreed to form a subcommittee to look at how this could be accomplished.

Paul Ballard summarized the legislative changes enacted in the 2013 session of the General Assembly related to care at the end of life. These included: House Bill 723 expanding the scope of a physician assistant's practice to include among other powers the power to sign a MOLST form, to give an oral DNR order at the scene with emergency medical personnel, and document an oral advance directive; Senate Bill 790 requiring that the Department of Health and Mental Hygiene set a fee to fund the advance directive registry and requiring the Department to make the registry operational by October 1, 2014; House Bill 581 requiring the Maryland Health Care Commission to select at least 5 pilot palliative care programs in hospitals with 50 beds or more and to gather data and issue a report regarding those pilot programs by December 1, 2015; and House Bill 1101 establishing the Natalie M. LaPrade Medical Marijuana Commission which will approve academic medical centers to operate medical marijuana compassionate use programs.

Delegate Morhaim reported that the medical marijuana bill passed with overwhelming bipartisan support. Delegate Morhaim also informed the Council that House Bill 690 was enacted, creating the Alzheimers' Disease and Related Disorders Council.

Lawanda Edwards stated the General Assembly has designated \$92,000 in the Department of Health and Mental Hygiene's budget for the advance directive registry. In accordance with Senate Bill 790, she stated they are going to urge the Department to make the advance registry a reality by October 1, 2014.

No further items of business having been presented, Chairman Meyerson adjourned the meeting.